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How to evaluate sexual health in cancer patients: development of the EORTC sexual health questionnaire for cancer patients

Eva Nagele¹, Brenda Den Ouden², Elfriede Greimel¹; on behalf of the EORTC Quality of Life Group

¹Department of Obstetrics and Gynecology, Medical University of Graz, 8036 Graz, Austria; ²Center of Research on Psychology in Somatic Diseases, Department of Medical and Clinical Psychology, Tilburg University, PO Box 90153, 5000 LE, Tilburg, The Netherlands

Correspondence to: Eva Nagele, PhD, MA. Department of Obstetrics and Gynecology, Medical University of Graz, Auenbruggerplatz 14, 8036 Graz, Austria. Email: eva.nagele@medunigraz.at.

Background: The aim of the study is to describe the development of a comprehensive European Organisation for Research and Treatment of Cancer (EORTC) questionnaire to assess sexual health of female and male cancer patients and for cancer survivors.

Methods: According to the EORTC guidelines, the development of an EORTC sexual health questionnaire is typically organised in four phases. The first phases comprise a literature search following interviews with patient and health care professionals (HCPs) (phase 1) and the operationalization into items (phase 2). The translation process is formally conducted according to the EORTC QLQ Translation guidelines with a rigorous forward-backward procedure supported by native speakers.

Results: Studies on sexuality in oncology patients which were identified by a literature search predominantly focused on issues of activity, experiences of sexual dysfunction, and satisfaction with sexual functioning. The literature review identified themes beyond these aspects. In total 53 potentially relevant issues were presented to 107 patients and 83 HCPs, different evaluations were found.

Conclusions: A questionnaire that includes physical, psychological, and social aspects of sexuality of cancer survivors will be needed. Pre-testing and validation of the questionnaire will be done in future (phases 3 and 4). Divergent ratings of patients and professionals should be further investigated.

Keywords: Cancer; sexual health; European Organisation for Research and Treatment of Cancer (EORTC) sexual health questionnaire

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Introduction

An individual's sexual response can be affected in a number of ways that involves the physical, psychological, interpersonal, and behavioural aspects of a person. The most common sexual problems for people who have cancer are loss of desire for sexual activity in both men and women, problems achieving and maintaining an erection in men, and pain with intercourse in women (1). Unlike many other physiological side effects of cancer treatment, sexual problems do not tend to resolve within the first year or two of disease-free survival (2-5) rather, they may remain constant and fairly

severe or even continue to increase. Long-term effects of different treatment on sexual functioning have been studied in cervical cancer survivors (6,7). Existing research has mainly focused on women who have breast or gynecologic cancer and men who have prostate cancer (8). Less is known about how other types of cancers affect sexual health. Although it is unclear how much sexual problems influence a survivor's rating of overall health-related quality of life, these problems are clearly bothersome to many patients and interfere with a return to normal post-treatment life. In 2014, the National Cancer Institute at the National Institutes of Health published data on some form of sexual

dysfunction occurring in 40-100% of persons diagnosed with cancer (1,9-13). Sexual dysfunction is less broadly defined than sexuality and is characterized by dysfunction of one of the four phases of the sexual response cycle, or pain during intercourse (14,15). The World Health Organization (WHO) defines sexuality as a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Comparatively, sexual health is defined as a state of physical, emotional, mental and social well-being relating to sexuality, and is not merely the absence of disease, dysfunction or infirmity (16). Cancer and cancer therapies are frequently associated with changes in sexual health. However, there is a lack of consensus regarding valid outcome measures for assessing sexual functioning in cancer patients (12,17). There is no single self-report measure that can be recommended for cancer clinical trials (18,19) on the basis of a broader definition of sexual health. Several modules for various cancer sites (e.g., breast, gynecologic, prostate) were developed by the European Organisation for Research and Treatment of Cancer Quality of Life Group (EORTC-QLG) which include a limited number of sexual functioning items. The U.S. National Institutes of Health PROMIS® Network has already developed a self-report measure of sexual function and satisfaction for cancer populations (20). However, the existing questionnaires do not cover the whole range of sexual health. Currently, there is no comprehensive instrument that assesses aspects of sexual health in a broader sense.

The aim of the study is to develop a comprehensive EORTC questionnaire to assess sexual health of male and female cancer patients and for cancer survivors. We describe the development of the sexual health questionnaire according to the EORTC guidelines (21).

Materials and methods

According to the EORTC guidelines (21) the development of an EORTC questionnaire is typically organised in four phases. The first phases comprise a literature search following interviews with patients and health care professionals (HCPs) (phase 1) and the operationalization into items (phase 2).

Literature search and interviews

The literature search is focused on sexual health in cancer patients with a search strategy which was kept broad. The

following combinations of keywords were used to identify papers in PubMed covering the period January 1993 to January 2012: 'neoplasms[mesh]' or 'neoplas*[tw]' or 'tumor[tw]' or 'tumors[tw]' or 'tumou*[tw]' or 'cancer*[tw]' or 'carcinom*[tw]' or 'oncolog*[tw]' and 'sexuality[mesh]' or 'sexual function or sexual function[all fields]' or 'sexual function[tiab]' or 'sexual dysfunction' or 'sexual dysfunction [all fields]' or 'sexual dysfunction[tiab]'. Articles focusing on sexuality that conceptually exceeds issues relating to sexual function, sexual activity or sexual response cycle in cancer patients and/or cancer survivors were selected through title and abstract screening. For inclusion, original research articles had to be full reports in English and published in peer-reviewed journals. Qualitative and quantitative studies are included in the review. Additionally, an evaluation of measures related to sexuality in cancer patients was conducted (Den Ouden *et al.*, unpublished data). Issues which resulted from the literature search were summarized in an issue list. The same list was then presented to patients and HCPs recruited by collaborators within the EORTC Quality of Life Group for feedback on appropriateness of content and breadth of coverage on a four-point Likert scale. The following demographic data from the HCPs were asked: professional background, cancer sites they were most familiar with, duration of being involved in the care of patients with cancer, sex and country. A case report form including the most important clinical data related to disease and therapy was given to patients. The list of issues was translated into several languages. Members and collaborators of the EORTC-QLG spread out the questionnaire to other HCP specialists in oncology such as psycho-oncologists, radiotherapist or gynaecologists in more than 20 institutions in different countries (Table 1).

For the final decision which issues on sexual health are definitely important for cancer patients, mean scores for relevance and priority ratings were defined according to the EORTC-QLG guidelines (21) using the following criteria: (I) mean score for HCPs <2 versus ≥2; and (II) mean score for patients <2 versus ≥2; (III) priority should have been rated by more than 30% of the HCPs; and (IV) >30% of patients as highly relevant to be included. Issues that met three or four of these criteria were kept in the list. Issues that met less than three criteria were deleted, unless the interviews provided strong arguments for retaining them. Additional new issues were included if they were mentioned by a considerable number of patients or HCPs. Based on the remaining issues the items for the provisional questionnaire were developed.

Table 1 Issue list

Sexual activity
Frequency of sexual activity
Reasons for being sexually inactive
Satisfaction with the frequency of sexual activity
Importance of having an active sexual life
Level of hesitation to initiate sexual activities
Sexual desire
Frequency of sexual desire
Level of desire
Distress caused by decreased libido
Satisfaction with frequency of sexual desire
Satisfaction with level of desire
Sexual arousal
Frequency of sexual arousal
Level of sexual arousal
Satisfaction with level of sexual arousal
Orgasm
Ability to achieve an orgasm
Difficulty to reach an orgasm
Satisfaction with the ability to orgasm
Satisfaction with the frequency of orgasm
Side-effects influencing sexual activity
Incontinence (urine/fecal) during foreplay or intercourse
Hair loss (indirectly) affecting sexual response
Fatigue/lack of energy affecting sex life
Scarring/organ loss (indirectly) affecting sexual response/satisfaction
Pain
Frequency of pain during/after sexual activity
Level of pain during/after sexual activity
Intimacy
Change in amount of affection expressed
The level of emotional intimacy
Satisfaction with level of affection or intimacy
Fear
Fear that sex will be painful
Fear of injury during intercourse
Fear harming the incision during intercourse

Table 1 (continued)**Table 1** (continued)

Communication/Relationship issues
Satisfaction communication partner
Partner is afraid to touch, afraid to cause pain
Experience of emotional distance from spouse
Insecurity regarding ability to satisfy the partner
Partner response to changes in sexual functioning: accepting/rejecting
Distress/bothered/satisfaction (general)
Level of comfort with one's sexuality
Change in presence sexual fantasies
Level of sexual enjoyment
Sexual satisfaction
Reduced sexual enjoyment
To what extent are sexual dysfunctions distressing
Health care/aids
Need for care because of sexual difficulties
Communication about sexual issues with health professionals
Male sexual health
Ejaculation
Dry orgasm
Retrograde ejaculation
Erectile function
Ability to get an erection
Ability to maintain an erection (firm enough for sex)
Satisfaction with ability to maintain erection or level of firmness
Level of confidence in getting an erection and keeping one
Masculinity
Change in masculinity/feeling less masculine
Female sexual health
Lubrication
Insufficient/decreased lubrication
Frequency of spotting/bleeding after sexual intercourse
Femininity
Change in femininity/feeling less feminine
Masturbation (included after discussion during an EORTC QLG meeting)

Operationalization into items

The process of translation is formally conducted according to the EORTC QLQ Translation guidelines with a rigorous forward-backward procedure (18) supported by native speakers. The underlying English issues will be operationalised into items first. If items already have been used in another validated EORTC questionnaire they normally are included in their original wording. Questions are phrased in a way that they fit into the 4-point answering format of the EORTC ranging from “not at all” to “very much”. A time frame of 4 weeks is chosen as suggested in the EORTC guidelines (21). A standardized introduction was modified for the issue of sexual health.

Phase 3 is the pilot-testing of the final item list and is actually under construction. A validation of the questionnaire will be done in phase 4.

Results

Results of the literature search

Many generic and cancer-specific sexual health issues have been identified in the literature review. A total of 4,518 articles were screened of which 3,461 articles were excluded because they did not focus on cancer patients and/or did not report sexuality as an outcome measure. Another 924 articles were excluded because they were literature reviews or presented only domain scores or were on sexual activity and sexual response cycle only. Finally, 65 articles were included in the systematic review. Apart from the frequency of sexual activity, sexual dysfunction and overall levels of satisfaction with sexual functioning, a number of issues were identified: sex-related guilt, anxiety, embarrassment, future prospects, quality of the relationship with the partner, changed feelings of sexual attractiveness, partner's response to the changed situation, and the effectiveness and side effects of (medical) sex aids. These topics were used as underlying issues for the provisional sexual health questionnaire.

Issues concerning sexual attractiveness were restricted to quantitative studies only. Many questionnaires for measuring different aspects of sexual health were found in the reviewed literature, but cancer-specific instruments were underrepresented. Sexual functioning was often assessed as part of (health-related) quality of life. Frequencies and sexual satisfaction were commonly assessed with a single item only. Qualitative designs to assess sexual functioning were used in 20 studies. The detailed results of the literature

review are described elsewhere (Den Oudsten *et al.*, unpublished data). Issues identified by the literature search were first checked for clinical relevance. A shortened list of 53 issues was then reviewed by a great number of patients (n=107) and HCPs (n=83).

Characteristics of patients and HCPs

Most of the patients had breast cancer (n=43; 40%), followed by colorectal (n=17; 16%), and head and neck cancer (n=14; 13%). All over the group cancer sites were well-balanced. The majority of patients were treated with surgery followed by radiation therapy and chemotherapy, and were under active treatment when they were interviewed. Half of the patients had no evidence of disease (n=53; 50%); a smaller number was newly diagnosed (n=17; 16%) or had a recurrent disease (n=11; 10%). A progression was stated for 10 patients. About a half had completed their treatment within the last 5 years, 8% more than 5 years ago and the others have not completed yet or did not provide any information on that. There were more female than male patients interviewed with a mean of 55 years (± 11). The majority was living with a partner or family and had a sexual partner and was well-educated (Tables 2,3).

Various experts from different disciplines, mainly employed as medical doctors (n=53; 64%), psycho-oncologists (n=16; 21%) or nurses (n=3), reviewed the issue list. Gender was equally distributed and their clinical experiences mostly ranged from 10 to 20 years. Most of the HCPs were familiar with gynecologic cancer (n=29; 26%), followed by colorectal/gastrointestinal (n=21; 19%), breast (n=18; 16%), prostate/testicular (n=9; 8%) and other cancer sites (e.g., head and neck or lung cancer) (n=33; 31%).

Interview results

Most of the issues on satisfaction as well as the importance of having an active sexual life were rated as highly important in the sexual health questionnaire by both patients and HCPs. There were several issues referring to satisfaction (e.g., satisfaction with the level of affection or intimacy, satisfaction with the frequency of sexual activity, satisfaction with the communication with the partner and sexual satisfaction). No specific issues for female patients were rated as highly important. Male patients additionally rated their level of confidence in getting an erection and keeping one as very important. These issues met all four criteria on relevance and priority. Issues on sexual arousal, orgasm-

Table 2 Sociodemographic patient characteristics (N=107)

Characteristics	N	%
Gender		
Female	66	62
Male	41	38
Age (years)		
20-35	3	3
36-50	31	29
51-65	54	50
66-85	17	16
Missing	2	2
Living situation		
Living with partner or family	90	84
Living alone	14	13
Living with others	2	2
Missing	1	1
Sexual partner		
Yes	90	84
No	15	14
Missing	2	2
Education level		
Post compulsory school education	47	44
University level	30	28
Compulsory school education or less	24	22
Missing	6	6

related issues and general issues on sexual enjoyment were also rather important for female and male patients and HCPs.

A very low relevance and priority had the issues on hair loss, masturbation and sexual desire (frequency, level). Also issues about fear harming the incision during intercourse, retrograde ejaculation and changes in sexual fantasies did not fulfill the criteria to be further included.

When considering the mean relevance only, all presented issues except five were more often rated as highly relevant for cancer patients by HCPs than by patients. There seems to be a similar relevance for sexual desire (frequency, level), satisfaction (with level of affection or intimacy and with the communication with the partner) and the level of emotional intimacy. All other issues were rated more relevant to be included in the questionnaire for HCPs, not for patients.

The greatest differences in the estimated relevance

Table 3 Clinical patient characteristics (N=107)

Characteristics	N	%
Treatment status		
Active treatment	72	67
No active treatment	34	32
Missing	1	1
Treatment		
Surgery	76	71
Radiation therapy	66	62
Chemotherapy	62	58
Anti-hormonal therapy	28	26
Others	5	5
Status of disease		
No evidence of disease	53	50
Newly diagnosed	17	16
Recurrence	11	10
Progression	10	9
Missing	16	15
Years since diagnosis		
Less than 5 years ago	80	75
5 to 10 years ago	20	19
More than 10 years ago	3	3
Missing	4	4
Time of completion		
During the last 5 years	45	42
More than 5 years ago	9	8
Not completed yet	4	4
Missing	49	46
Menopausal status (N=66)		
Post-menopausal	30	45
Pre-menopausal	19	29
Treatment-related menopause	13	20
Missing	4	6

(>1.10) were found for issues on incontinence, masturbation, pain and fear, always rated higher by the interviewed HCPs (>1.0). Comparable results were found for issues for male sexual health (ejaculation) and issues on masculinity/femininity (Tables 4,5).

Priority for inclusion was assessed in the same way for most of the 53 issues from the list. Only level of emotional intimacy and change in amount of affection expressed was

Table 4 Mean relevance for issues rated similar by patients and HCPs

Issues	Mean relevance	
	Patients	HCPs
Frequency of sexual desire	1.76	1.76
Level of desire	1.70	1.79
Satisfaction with level of affection or intimacy	2.24	2.31
The level of emotional intimacy	2.10	2.13
Satisfaction communication partner	2.35	2.43
HCPs, health care professionals.		

Table 5 Mean relevance for issues rated different by patients and HCPs

Issues	Mean relevance	
	Patients	HCPs
Incontinence	0.87	2.39
Masturbation	0.88	2.02
Frequency of pain during/after sexual activity	1.39	2.54
Level of pain during/after sexual activity	1.26	2.57
Fear that sex will be painful	1.06	2.46
Fear of injury during intercourse	0.87	2.08
HCPs, health care professionals.		

much more higher prioritised by patients than by HCPs. Although many issues on body-related changes were less relevant for patients on average, they thought that these topics should be included in such a questionnaire of sexual health for cancer patients anyway (e.g., incontinence).

Highest differences in the evaluated issues, identified for relevance and priority, were found for frequency of pain (during/after sexual activity), incontinence, fear that sex will be painful, and for communication about sexual issues with HCPs. While the interviewed HCPs found those issues more important to integrate in the sexual health questionnaire, patients found them less relevant.

Item development

On the basis of the results a provisional item list was established ("EORTC SHQ-Cxx"), supported by the translation coordinator of the EORTC Quality of Life Department. Issues fulfilling all four criteria on relevance and priority were automatically included. Issues within the categories of sexual desire, sexual arousal and pain were combined each. Issues implying norms, such as frequencies or content-related redundancy were not included. Negative

wording or ambiguity was additional reasons for exclusion. The reduced list of 22 items with an additional question on reasons for not being sexually active was reviewed by two independent native English speakers before starting the translations process. At least three languages representing an English-speaking country, a country from Northern and Southern Europe were invited for preparation of pilot-testing, which is the next step in the EORTC procedure to develop a validated EORTC questionnaire.

Discussion

The results of the literature search were considered for the development of the issue list which was presented to patients and HCPs. Interview results were then analysed and item development process was done before continuing with pretesting.

Studies on sexuality in oncology patients which were found in the literature search predominantly focused on issues of activity, experiences of sexual dysfunction, and satisfaction with sexual functioning. The literature review identified themes beyond these aspects and provided interesting results on current instruments used for measuring sexual health. No questionnaire currently exists that focuses on physical, psychological, and social aspects of sexuality for cancer survivors. Based on the available interview results most important issues to fill this gap were identified: satisfaction and the importance of having an active sexual life such as the level of confidence in getting an erection and keeping one for male patients. Different evaluations by HCPs and patients were found for most of the issues. Pain, incontinence, fear and communication about sexual issues with HCPs were issues which were highly relevant for HCPs but not for patients. Less research exists, in which possible reasons have been identified. Body image can change during different phases of cancer treatment. As shown in a review article by Cororve Gingeret *et al.* 2014 (22) patients are found to be most concerned about body image in the immediate postoperative period and soon after completing other forms of treatment (23). In a study with 225 Canadian cancer patients, 44% used the Internet to learn more about their condition and 14% wished their medical teams had provided them with links, but did not independently search for medically relevant information about their condition. While education level was correlated with web based information seeking, age was not (24). Why fear as an issue was less important for our interviewed patients than for professionals would be

interesting to further investigate.

Strength of the study is the fact that the development of the sexual health questionnaire is based on current literature, patient and HCP interviews from many different countries according to the EORTC guidelines (21). The literature review systematically examined sexual health issues in cancer beyond general ratings of sexual activity, symptoms, and sexual dysfunction. As other literature reviews (25–28) have described patients' sexual activities, types of sexual dysfunction and generic levels of sexual satisfaction, this review uniquely took as its focus sexual health issues for all cancer patients and survivors. Including interviews of more than 100 patients with different cancer sites and many professionals from different disciplines also increases the quality of the development process. The provisional module will then be pre-tested in various languages to identify and solve potential problems with wording. For pilot-testing patients from many different countries and cultures are foreseen (phase 3) after the translation process was finished and ethical approval was done. Also the translations into several languages and the cross cultural distributions for developing the questions follow a standardized procedure (18). The questions are designed for male and female patients with different cancer sites during all stages of their disease.

It is suggested that future studies broaden their focus to encompass sexual health related topics (body image, self-esteem, relationship functioning and communication) rated as important in cancer survivors which is not evident yet. But these issues should be addressed in clinical trials to get information on a possible impact for clinical practice. The instrument will be designed as a 'stand-alone' sexual health measure that can be used in clinical trials as well as in clinical studies. The results of trials which use the sexual health questionnaire adequately can improve sexual health care.

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